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Ticket to Talk: Supporting Conversation between Young People and People with Dementia through Digital Media

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ABSTRACT

We explore the role of digital media in supporting intergenerational interactions between people with dementia and young people. Though meaningful social interaction is integral to quality of life in dementia, initiating conversation with a person with dementia can be challenging, especially for younger people who may lack knowledge of someone's life history. This can be further compounded without a nuanced understanding of the nature of dementia, along with an unfamiliarity in leading and maintaining conversation. We designed a mobile application - Ticket to Talk - to support intergenerational interactions by encouraging young people to collect media relevant to individuals with dementia to use in conversations with people with dementia. We evaluated Ticket to Talk through trials with two families, a care home, and groups of older people. We highlight difficulties in using technologies such as this as a conversational tool, the value of digital media in supporting intergenerational interactions, and the potential to positively shape people with dementia's agency in social settings.

Author Keywords

Dementia; technology; intergenerational; communication; families; volunteers.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

INTRODUCTION

Over the past decade, a growing interest in the HCI



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community has formed around dementia, highlighting it as a complex and important topic requiring careful and sensitive approaches to research [10,22,28,32,37,39]. This approach is especially necessary when designing for communication and dementia. Communication is integral to delivering effective, person-centred care and boosting mental well-being in people with dementia [9,24,27,53,54,60]. For someone with dementia, communication and reciprocal relationships are paramount in maintaining a sense of identity [51]. Despite this, it has been reported that the majority of care home residents with dementia experience loneliness [42], and there are well-acknowledged issues that carers and family members can become reluctant to converse with, or spend extended periods of time with someone affected by the condition.

There is advice for communicating with family members with dementia [3,4,41], however these challenges are compounded for younger family members and young carers. Young people not only describe a lack of knowledge of the complications of dementia [36,59], but sometimes lack knowledge of the person affected by dementia's past experiences. Furthermore, a lack of shared interests further inhibits the instigation of conversation with people with dementia [36]. Generational gaps between young people and people with dementia can form barriers, creating unfamiliarity with an older person's experiences and often forming the root of these conversational difficulties [45]. Recent research in intergenerational interactions within dementia have shown that, along with the challenges of starting a conversation, young people can often be ill-equipped to effectively deal with the difficulties of the condition itself and managing unusual behaviours presented by dementia [21,36].

In this paper, we report on research examining the role of digital media in supporting conversations and social interactions between young people – be they young family members, or young people working or volunteering in care contexts – and people with dementia. We build on our previously published work with young people, exploring both their experiences of dementia, and the opportunities

for technology to respond to and ameliorate some of the issues that they faced. This prior work highlighted how young people face a range of challenges when socialising with older people with dementia, including anxieties around how to initiate, direct and respond to conversation topics. Many participants also highlighted concerns around what topics to talk about with their elder family members, in part due to a feeling of not knowing them well-enough.

In response, we developed Ticket to Talk; a mobile application designed to stimulate talk between young people and older people with dementia. The application: supports the creation of a personal profile for an older relative or person the young person cares for; prompts them to collect media (photographs, imagery, video and sound clips) related to the events in the person with dementia's life; helps them organise these into playlists of related media; and use them as prompts and conversation starters.

In this paper, we report an evaluation of Ticket to Talk through a series of engagements with: i) two multi-generational households where an older family member had dementia; ii) three young people who were starting volunteering activities in a residential care home; and iii) nine older people with an interest in and personal experience of dementia, in an expert critique workshop. The findings from our studies highlight two contributions to the growing literature in HCI on designing technologies for and with people with dementia. Firstly, we highlight the value of conversational tools to support young people in their interactions with people with dementia. Secondly, we highlight the positive and negative ramifications of such a conversational tool's influence on people with dementia's agency in social settings.

BACKGROUND

Digital Reminiscence

Person-centred care is a common approach in caring for people with dementia, aiming to treat each person individually through understanding the nuances of their personality and their experiences of dementia [13,14,25,26]. Person-centred care outlines the need for consistent reaffirmation of self - which involves understanding a person's lived experience and celebrating their stories, passions, and idiosyncrasies - as a corrective against care practices that treat people with dementia primarily as medical cases of cognitive and social decline [25]. There are well-studied examples of resources supporting carers working in care homes to stimulate reminiscence with people with dementia. One prominent example, Life Story Works (LSWs), supports the gathering of media - such as collections of photos, texts, or life story books - to then be used in a person's care. McKeown et al. [34,35] review the use of LSWs in care homes, highlighting how the compilation of these works encourages interaction between staff, families, and the person with dementia. They describe how this can present the opportunity for improving relationships within the dementia care ecology, through the act of curating such media. Opportunities to share their

LSWs were seen as social occasions centred around sharing the people with dementias' experiences - leading to changed perceptions of the care home residents through these expressions of personhood.

Recent work within the HCI community has explored the role of technology in reminiscence and LSWs, with Lazar et al.'s [29] recent systematic review of technologies for reminiscence from functionally-oriented systems (e.g., those compensating for memory deficits [30]), to designs focused on bringing forth emotional memories and experiences (e.g. reminiscence activities based on football teams [52]).

Encouraging reminiscence through technology has been directed at both formal and 'informal', or unpaid, caregivers. Maiden et al. [33] explore the use of mobile applications for reflection by encouraging carers to log and then reflect on their interactions with people with dementia, prompting them to think about methods in which they can deliver a better approach to person-centred care. Wallace et al.'s 'Tales of I' [53] focuses more explicitly on the individual with dementia, showing memories or films through an interactive art piece in a care home. In other related work, Wallace et al. explored personhood through reminiscence with a couple (Gillian and John) through a series of bespoke design probes [54]. Responses to probes informed a series of digital jewellery designs, which focused on supporting reminiscence to both connect Gillian, John and their children around life events, but to also support sense-making around ongoing events in their lives and a legacy for the future.

Dementia and Family Dynamics

Ryan et al. [48] explored the effect of dementia on family roles, noting some of the difficulties in experiencing a change from a valued family member to a care receiver. Ryan et al. used writing as a way to reclaim some sense of social identity, helping family members to see past a relative's dementia through a creative expression of their thoughts and emotions. Similarly, Wallace et al.'s [54] work, noted above, highlighted the ways that co-created activities around design probes supported shared activity and re-connected loved ones who may be struggling with a diagnosis of dementia.

There is a dearth of work focusing on the impact of dementia on the extended family, with research typically focussing on the primary caregiver (e.g., a spouse or formal carer), the person with dementia, or their relationship. A family unit may be a challenging area for design, often requiring a sensitive and empathetic approach. Wright & McCarthy [56] outline the importance of empathy in understanding those that use the technologies we design, helping to employ a pragmatic approach with respect to a nuanced understanding of someone's experiences and perceptions. Lindsay et al. [32] also note the value of empathy as an approach to design, helping designers and people with dementia reach a common understanding of a

lived experience - navigating the sometimes confusing social dynamics in dementia care ecologies. An empathetic approach has a value in approaching complex settings, such as understanding and designing for the changing social dynamics between people with dementia and their younger family members. Hall & Sykes [21] noted younger children find the relationship with an older relative difficult, leading many to reconceptualise their relationship, resulting in a family role reversal, where they now provide care for their older relative. Young people may often lack knowledge or awareness of their older relative's life histories, making the relationship more difficult to maintain, and social interactions less memorable or positive. The Alzheimer's Society give advice to young people about this role reversal [5], as well as guides on teaching young people about dementia [6], but fail to offer advice specifically on communicating with people with dementia.

In exploratory workshops with younger carers we discovered, despite the complexity of dementia, younger carers of people with dementia found the generational gap between themselves and older relatives to be the main barrier towards positive social interactions. In previously published work [36], we cite that younger carers are placed in positions where they need to drive conversations yet are not equipped with the knowledge of the person's past or are unfamiliar with an era their relative is most likely to remember. In cases such as this, supportive curation of meaningful media may aid and enrich social interaction.

Digital Media and Dementia

Digital media has been used to stimulate interactions within care homes [1,16,20,46,49], many of which stimulate conversation between care home residents through sharing common media from past eras, such as CIRCA [2,20], and Chitchatters [46]. Others take a more person-centred approach designed for interactions between residents and visitors, taking the form of multimedia biographies specifically tailored for each individual [49]. These technologies allow carers and volunteers to interact with residents at a much more personal level, unlike those of the interactions created by CIRCA and Chitchatters, which encourage interactions between residents themselves.

The research above places a strong focus on visual media to stimulate communication, however other research has found music to act as a stimulating resource, capable of bringing many residents together in engaging activities. Uses of music range from expressing creativity through forming simple chord progressions [47] to using media and technology to engage with a care home as a whole [38,40]. Morrissey et al. [40] show how "SwaytheBand", a baton which responds with glowing lights to a predefined list of music, can have a positive effect on residents' social roles within a care home. Creating group sessions using the technology with an accompanying list of songs transformed stagnant interactions into ones where residents actively engaged with each other and staff. TV has been used as a source of media to act as "tickets-to-talk" [50], helping

older people talk with other members of the community over a shared activity of watching TV. Blythe et al. [9] build on the concept of "ticket-to-talk" by working collaboratively with an artist and children from a local art club to experiment with projected drawings in care homes. Residents were drawn whilst their in-progress portraits were projected to the rest of the room. Blythe et al. describe this as being an effective "ticket-to-talk", encouraging communication and engagement in the care home. Furthermore, Blythe et al. cite that the children from the art club acted as a great "ticket-to-talk" in their own right, noting the intergenerational interaction was hugely exciting and stimulating for the residents of the care home.

Apart from exceptions such as Blythe et al.'s work, there is still relatively little research that has explored ways of stimulating intergenerational interactions in the context of dementia. We have attempted to bridge this gap in our own prior work, which has motivated the design of the Ticket to Talk system. In the following section, we briefly review the findings of this prior work, and how it has fed into the design of Ticket to Talk.

TICKET TO TALK

In previously published work, we identified younger people's specific needs when engaging with people with dementia, in collaboration with a local charity. This was approached through co-design workshops, aimed at exploring young people's personal experiences of dementia care. In this previous work, we enacted design concepts drawn from an understanding of personal experience, where we further refined ideas of supporting intergenerational communication in dementia care. One of the concepts developed in this past work explored how a curated set of assorted media can form conversation 'ins', allowing younger family members to engage with an older relative with dementia [9]. This is expressed in one of the major themes discussed by young people, that despite having a strong desire to engage in positive social interactions with relatives who have dementia, a perceived generational gap created difficulties in initiating and maintaining conversations. This project expands the 'Ticket to Talk' idea, developing it into a mobile application, offering younger people the chance to create talking points around a curated set of personalised media.

A common use case of the application would be: a younger person creates a profile of an older relative with dementia, then invites family members to the profile. They then add an assortment of media (photos, sounds, videos) to the profile to use as talking points with an older relative. The younger person would then compile this media into playlists, in preparation for their next visit. Finally, the application would be used in conversation, using the playlist they have made and showing their media. These stages are discussed in further detail below:

Setting up a profile: On first use, the application prompts the user to create a simple profile based on an older relative

or friend. Illustrated in (Figure 1-1), this profile contains an optional photo of the relative, basic biographical information (which is used to personalise the application), and a description of their condition. At this stage, the young person can invite other people (family, friends, or carers) to contribute to this profile, giving them access to the tickets they themselves have created, but also allowing the rest of the care circle to upload media.

Inspiration: A core feature of the application is providing inspiration to the user about what media to use as tickets to support talk (Figure 1-2). This feature was grounded on learning from the previous co-design work which highlighted that young people benefitted from prompts to stimulate ideas around what types of media to collect that may have meaning for an older relative or person they care for.

Ticket to Talk provides inspiration in the form of generic suggestions, personalised with information from the older person's profile. These prompts typically invite the young person to find out a bit of information about the life history of the person they are creating tickets for, and to create media related to this. For example: "Steven was 18 in 1940, can you find a picture of London at that time?"; and "Stephen was 25 in 1947, try and find out the number 1 news story for that year". The events featured in the inspirations aim to explore memorable experiences, occurring mainly during early adulthood. This capitalises on the effect of the reminiscence bump in the older relative [23], focussing on big events such as marriage and building a household. The prompts also steer the young person to gather a range of media, diversifying the material. For example, the application may ask them to collect a 'sound' of an event rather than a picture or piece of music. Ticket to Talk then encourages engagement with a person with dementia's life, uncovering their interests and navigating past experiences.

Collecting media: As noted above, Ticket to Talk allows the younger person to capture a wide range of different media, such as: photos with the device's cameras, audio

using the device's microphone, or adding links to YouTube videos (see Figure 1-3). These items of media are attached to a profile of an older relative, where the media is uploaded to the server and synced across other contributors' devices. Media can be collected directly from the inspiration prompts above; also, the younger person can upload content directly to a profile if they have ideas of what might make a stimulating ticket.

Preparing conversations: As a conversational tool, Ticket to Talk encourages the creation of 'conversations', before it is used in practice (Figure 1-4). Conversations are a curated set of tickets, representing a music playlist or slideshow, holding accompanying notes for younger people to log their observations to reflect on before future conversations. The younger person can use these 'conversations' when they are with older relatives, as a backup if their conversation were to stall. After using a prepared 'conversation', users are prompted to record their reflections of how the conversation went, how specific tickets worked, and what they might do differently in the future. These observations are then uploaded to the server and synchronised between all of the contributors' devices.

Implementation

The application was built on the Xamarin.Forms framework [57], creating a cross-platform application available on any mobile device or tablet, running the iOS or Android operating systems. Using an API built on the Laravel framework [43], a MySQL database stores user information along with an Amazon S3 Bucket [7] to store users' media. Security policies enforced on the backend ensures tickets are shared only with people the administrator of the older relative's account deem appropriate. Given the somewhat sensitive nature of this information all data regarding people with dementia is encrypted using the AES-256 standard [17].

STUDY DESIGN

In order to study the potential for the Ticket to Talk application to support intergenerational conversation, we studied it in three distinct settings: with families, wherein a

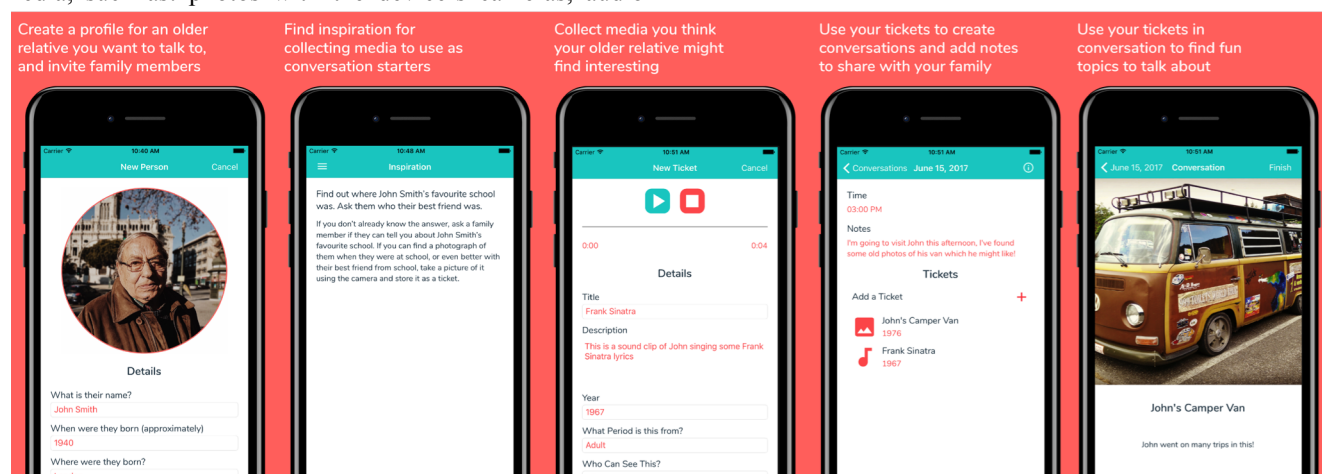


Figure 1: Screenshots from ticket-to-talk.com showing the different stages of Ticket to Talk: 1) creating a profile; 2) finding inspiration; 3) collecting media; 4) creating conversations, and lastly 5) using the media.

group of families were interviewed before and after the use of Ticket to Talk; with young people volunteering in a care home; and finally, through expert critique by older people. This was to evaluate the application within the different social settings it may be employed in in practice, as well as means of mitigating any effects from a smaller sample size. We describe each of these in the following sections.

Deployment with Families

Two families were recruited to help evaluate Ticket to Talk. Family 1 consisted of an older man in his 90s living with dementia in a private care home, as well as his daughter and grandchild who visited him daily. Family 2 consisted of an older woman also in her 90s, along with her daughter and son-in-law and their four children. The family lived in a different city from their older relative with dementia, but visited frequently.

Families used Ticket to Talk for 3 weeks, with a group interview at the start and end of this period. Questions were directed towards the whole family in a group interview, exploring the relationships with the family member living with dementia. The first interviews explored three topics: current communicative practices between younger family members and their older relatives (“Can you tell me about how your family communicates/keeps in touch with you?”); how this has changed with the progression of the older family member’s dementia (“Can you tell about how recent memory problems might have changed how you communicate as a family?”); and the use of media as a conversational aid (“Can you tell me about how the family photos help to get conversations started?”). Following the first interview, families were asked to use Ticket to Talk to create a profile for the family member with dementia and start collaborating in collecting media, and use it in conversation over the next 3 weeks. Following this period, we asked participants to reflect on their use of Ticket to Talk. At appropriate points, we would probe the nature of the family’s communication with the relative who has dementia after the introduction of the technology (“Can you tell me how Ticket to Talk might have changed your conversations?”), and explore the use and efficacy of digital media in supporting intergenerational interactions (“How has the topics of conversations changed from using Ticket to Talk?”). The family’s tickets were used to prompt these discussions.

Deployment in Care Home

Ticket to Talk was also used by three young volunteers in a care home, to help stimulate and maintain conversations with residents. There were 10 participating residents, all within the ages of 80-95, with moderate or severe dementia. There were 3 volunteers (aged 22-28) with differing levels of experience of volunteering in care homes (from none to a regular visitor) and different levels of familiarity with the residents (from strangers to friends).

This deployment saw volunteers and residents using Ticket to Talk for 4 weeks across 6 visits. The first stage involved using Ticket to Talk with a single resident, connecting with

them on a personal level over multiple visits. Firstly, volunteers used historical pictures of the local area to gain some knowledge of this person’s life history. Secondly, volunteers created tickets based on this knowledge to use in their next visit. Finally, after using their tickets in conversation, volunteers then created a set of more refined tickets, reflecting a more nuanced understanding of the person’s identity and past experiences from their last visit. This resulted in 20 tickets, many tailored towards this resident’s life history, but also general tickets on the local area. The second stage used Ticket to Talk as a group activity. The application was used on a tablet by volunteers and a senior nurse, which was passed around the group of residents. The tablet showed generalised tickets for the whole care home about the local area, including changes to the city in recent years, along with past prominent politicians and activists.

Expert Critique by Older People

The final study setting was an expert critique from older people. To facilitate this, we ran workshops with 9 older people aged between 65 and 80. Participants self-identified as having personal or professional experience of dementia, and stated an interest in intergenerationality. The workshop was designed to support critique of Ticket to Talk, drawing on participants’ own experiences of communicating with people with dementia.

In this workshop, participants were given a smartphone with Ticket to Talk installed and were shown its intended use. After becoming acquainted with the application, participants were split into small groups of 4 to 5 people and critiqued the application, following Frohlich et al.’s technique of identifying elements to keep, change, and lose [18]. A final collective group discussion identified key elements that they: 1) deemed essential, 2) thought required refinement, and 3) were a hindrance to supporting intergenerational interactions within dementia.

Analysis

Interviews and workshop discussions were audio recorded, which were then later transcribed by the lead researcher. Data from the family consisted of rich group interview data focussing on reflections of the use of Ticket to Talk, where responses were explored and deliberated over as a group. Data collected from the workshop was in the form of group and collective discussions on different aspects of the application and problem space. Field notes were used to record the interactions and experiences in the care home setting. We conducted thematic analysis [11,12] over the entire data set, in which themes are identified as patterned responses in the data set. Data was analysed inductively, without theoretical expectations or preconceptions of the meaning of results from the data set.

Transcripts were re-read after transcription and coded, e.g. “Conversations are centred around the past”. Transcripts were revisited after the initial coding stage, refining the codes into something more focussed, e.g. “Conversations about the present are overwhelming”. Codes were grouped

to form candidate themes such as ‘shifting social roles’, these were later refined into a set of encompassing themes.

Ethics

Ethical approval for the studies was granted by two of the authors’ institutions. Approval for the family study and expert critique required that consent be given freely by all participants, including participants with dementia. Where studies involved being with participants with dementia, time was taken to go through a full consent process on first contact with participants in line with the Mental Capacity Act (2005) [44], ensuring participants understood the purpose of the study, their involvement, and the information. Furthermore, participants had to be able to make a decision on this information and communicate this back to the researchers. Family members and other carers were precluded from giving consent on the part of their relatives with dementia.

FINDINGS

Our analysis led to the generation of 3 themes: 1) Promoting and Managing Reminiscence, 2) Starting and Maintaining Conversation, and 3) Redistributing Agency. These themes are discussed in the following sections, where all participants are given pseudonyms to protect their identities.

Promoting and Managing Reminiscence

Families described their use of Ticket to Talk, highlighting an aim to provoke reminiscence. These tickets were used to construct comfortable conversations for both the young people and people with dementia, by presenting topics upon which they could jointly reminisce. However, participants argued tickets should try to encapsulate the full spectrum of emotion, allowing people with dementia to experience more than positive nostalgia. In example, Lucy warns her family about shielding their grandmother:

“... she’s allowed to feel different emotions, like we can’t just be like “Oh, let’s have lots of tickets about really happy lovely things.”. There are some things where you want to acknowledge the sad things as well.” Lucy, Family 2.

Lucy reflects on the tickets her sisters had created for their grandmother, noting the use of positivity to shield from negative emotions. Participants signalled tickets were commonly a shared point of reminiscence, reflecting conversations younger people had held with their older relatives prior to the introduction of the technology. These tickets embodied the idea of “safe” reminiscence, and younger relatives used Ticket to Talk to form a collection of conversational anchor points, allowing them to use the application to form a conversation quickly, which avoided uncomfortable territories:

“We’ve definitely got certain kind of conversation touch stones that we can always go back to, even if it does get a bit repetitive.” Philippa, Family 2.

In contrast, when using more generic tickets in a care home, volunteers lacked an insight into someone’s life history and

could accidentally instigate a more divisive or emotive conversation. For example, profiles of a political figure of the 20th century prompted debate amongst the residents as they disagreed on the merits of the politician. Similarly, photographs of well-known landmarks, which may seem ‘safe’ can have ties to negative emotions, unforeseen by young volunteers. This was observed in our field notes during a group activity using tickets:

Next was a picture of the old Swimming Baths. Some of the residents said they knew it very well and could speak about some of their memories of happy days at the Baths. When asked, one of the residents Anne, talked about how they had separate days for the girls and boys, and she knew a boy who wouldn’t go in on the girls’ day, and instead went up the river to swim and drowned.’ Field notes.

Though it might mean avoiding important topics, participants sometimes used Ticket to Talk to repeat previous conversations in order to avoid uncomfortable situations. This was used to avoid situations where an older person would be unable to remember a story, or follow a story a younger person shared about their recent experiences. Reminiscence then formed the default conversation format with Ticket to Talk, creating a feeling of safety and comfort for both parties. However, using Ticket to Talk for reminiscence required a collection of shared experiences to be effective. Participants from the critique workshop presented criticisms of Ticket to Talk’s retrospective influence on creating tickets, stating that reminiscing over a topic is not a complete conversation:

“You know, the person’s background, their history, is not the only thing, not the total conversation.” Erin, Workshop.

Erin, who cares for her mother who lives with dementia (where her mother was present at the workshop), indicated using Ticket to Talk for reminiscence fails to form a complete conversation as it can exclude an older relative from sharing their own stories. It can also hinder older relatives in discussing aspects of their younger relative’s life. Other participants discussed reminiscence, favouring it as a conversational device for its therapeutic qualities and sanitisation of negativity. Eric describes how he would form conversations with friends with dementia:

“I don’t have much experience, but I think keep away from anything negative, things that have upset them in the past. A distraction rather than something to talk about.” Eric, Workshop.

Instead of engaging in a relational exchange with someone with dementia, people with dementia are instead distracted with reminiscence. Participants discussed how conversations using Ticket to Talk could become superficial if a string of conversational anchor points were used to create a conversation, potentially becoming repetitive if a young person lacked a wealth of shared experiences to draw from. In the absence of shared experiences, conversational anchor points became broader

and reminiscence became more difficult to instigate. However, for some, using Ticket to Talk inspired them to expand their knowledge of their older relative's life history:

"I have to say this gave me a bit of a boost to go and get the sheet music and bring it here." Alice, Family 1.

Alice noted how Ticket to Talk inspired her to collect sheet music, so that they might reminisce over it - giving her an opportunity to learn more about her relative's interests and past experiences around the media. Data suggests using Ticket to Talk to help reminisce creates a feeling of safety when conversing with people with dementia, giving a sense of comfort for younger people in sometimes difficult social settings. Yet, there are concerns that, in only using Ticket to Talk to reminisce, conversations could become sanitised of negativity to encourage younger people to talk to people with dementia.

Starting and Maintaining Conversation

Younger people found starting and maintaining conversation with people with dementia difficult. Participants discussed that despite the conversational aids, the difficulties of talking to someone with dementia still presented a steep learning curve, especially in the appropriate use of digital media such as Ticket to Talk. For example, participants noted how Ticket to Talk highlighted the need to take a sensitive and empathetic approach to avoid interrogating someone with dementia:

"I would never – I wouldn't want to put a ticket where I felt like I was like 'Remember this? Remember this? Remember when we did this?'" Philippa, Family 2.

Young people are careful to avoid using Ticket to Talk to test people with dementia on their memory, echoing their approaches in prompting reminiscence outlined above. Participants stated testing may lead to feelings of frustration should someone with dementia be unable to recall details, but also makes younger people uncomfortable when the effects of dementia on memory are brought to the centre of focus. This pattern of conversation was further discussed in the workshop, specifically how Ticket to Talk can promote asking questions, which can be challenging for people with dementia:

"... you can be led into questioning all the time. That's really not helpful. When you say 'Can you remember?' ... I listened to an expert recently saying this. We tend to say do you remember this or do you remember that? And they can't. It's not helpful." Paul, Workshop.

The inability to use questions as a conversational device was seen as a further barrier to instigating conversation, putting additional pressure on young people to employ a creative and sanguine outlook towards new methods of communication. During the workshop, participants gave suggestions of using Ticket to Talk to give younger people advice on exploring communicative methods, in the hope it might help start conversations with people with dementia:

"...you have to try various ways, you have to brief the person that's making the conversation, making the point of contact, making the conversation flexible, being prepared for reaction and non-reaction." Eric, Workshop.

Eric explains how younger people need guidance in starting and maintaining conversations with people with dementia, especially in taking a sensitive and empathetic approach. Younger generations need to be aware that communication may be non-verbal and responses to a topic may change from one interaction to another, but that should not be a reason to avoid communicating with an older relative who has dementia. However, despite the learning curve in the appropriate use of media and the need for motivation in exploring the different means of communication, younger people reported Ticket to Talk gave them a boost in confidence when conversing with people with dementia, knowing that there was a readily available store of topics they could use to maintain a conversation.

"I could have my phone, and I can always check my phone if you know I'm struggling of things to think of, and it's the confidence that conversation is going to keep going, and you've got ideas of what to say to her that she's going to remember and know about and have input for." Philippa, Family 2.

Philippa describes a newfound confidence in talking to an older relative, making her more likely to start future conversations. Ticket to Talk helped start conversations in the care home as volunteers met and spoke to residents they had not met before. Noted in our field work, Ticket to Talk helped start a conversation with a collection of photo tickets, but then allowed the volunteers to maintain the conversation unaided:

While the photos got our conversation started, we also spoke for a long time after in more of a group. Field Work

Ticket to Talk helped volunteers start a conversation using tickets on the local area, enabling them to quickly build the rapport needed to maintain the conversation without further assistance from Ticket to Talk. These findings highlight some of the difficulties in starting and maintaining conversations with people with dementia, also showing how Ticket to Talk can be used to give the confidence needed to start conversations and the necessary tools to maintain them.

Redistributing Agency

Through the use of Ticket to Talk and discussions of the use of tickets, a sense of the redistribution of agency was identified. Participants signalled a reconfiguration of conversational power dynamics through the use of digital media, letting someone with dementia lead the conversation. Discussing the deliberate shift in agency during the workshop, Paula confessed to using the application some time before the session to create a profile for herself, and store some of her memories for safe keeping:

“... none of us know when it might happen to us so wouldn't it be a good idea to use it to put our information in so that if something does happen your members of your family who have access to your phone can look at it and say that's actually quite useful. It's fantastic because they can look at it.” Paula, Workshop.

This shows a deliberate attempt to redistribute agency when Paula attempts to retain control over her future interactions with her younger relatives in later life, should she ever develop dementia. This is approached through preserving her current interests and past experiences. People with dementia rarely have the opportunities to shape their interactions, and as the condition continues, communication can grow ever harder. Participants signalled preparation like this can ameliorate communication for younger people as interests and a record of someone's life story is readily available, but more importantly, this life history is a version of the older person's choosing. This selection over what younger people can use as conversational topics is what enables this retention of control. Participants also discuss how using Ticket to Talk to configure social situations can further this redistribution of agency, especially in everyday conversations. Older relatives are generally spoken to in a superficial, or functional manner, *“...it tends to be functional conversation, rather than an enjoyable conversation.”* (Alice, Family 1), but with Ticket to Talk people with dementia can be positioned as leaders in conversation, sharing their stories and advice:

“... what you can do is present an issue. You can say look you know, I can't do this, what do you suggest? ... They must not be treated as people who don't have any opinion, at all, no, like they don't know what's going on or how to do things. They still do. So, I think you have to also allow them to be involved in your problems...” Erin, Workshop.

This theme is further developed through a series of conversations with Family 1 while creating tickets in a group session with Bob, his daughter Alice, and the researcher. Creating tickets and asking Bob what stories he would like to share with his younger relatives completely changed the previous power dynamics in the social situation, suddenly affording him much more agency. The quotes below show a series of prompts regarding Bob's visit to the 1958 World Fair where Alice attempts to position Bob as the leader of the conversation, and share his experiences of the event with herself and the researcher:

“...you know you went with Mum to the world fare in Brussels in 1958, you were representing your company I think?” ... “The only other thing I can remember about it was - You - Did you not meet Mrs. Bandaranaike?” ... “Could we make a ticket out of that then? Because I'm sure that they - the grandchildren would be really interested.” Alice, Family 1

Alice successfully encourages Bob to share this story after a series of prompts. Bob is provoked multiple times to broaden Alice's understanding of his experience until he

complies. Alice then takes steps to preserve this experience as a ticket, giving other family members the necessary conversational devices and knowledge to position Bob as the leader of the conversation, without the need for multiple prompts. Future conversations are eased for the rest of the family members and future interactions for Alice, as their knowledge of Bob's past experiences are broadened, allowing them to engage in casual reminiscence and maintain the style of safe conversations younger relatives enjoyed above.

When tickets deviate from safer topics of conversation, such as the social and political climate of the 20th Century, they allow for more serious conversations. In these conversations, people with dementia can still express opinion and debate with younger people. These conversations positioned the residents as informed adults, not always highlighted within dementia care. In the care home, a discussion began around a ticket on the socio-political climate of the 20th century, as demonstrated in the below field notes:

A conversation starts about a famous politician, and I ask the resident beside me if she likes him. ‘Yes,’ she nods. She's been very quiet up to now but she starts to tell us that her husband's cousin heard the shots that killed him. I download a picture of it and she confirms that it's the place, nodding her head again. She's very knowledgeable about this topic and becomes the person we turn to when someone gives their opinion. I'm surprised at this, because during other activities she struggles to keep up with what's happening, whereas here, in this conversation, she has become the expert. Field Notes

Following a potentially antagonising topic allows debate amongst the residents and for some to lead the conversation, this allows younger people to further explore their interests and lived experiences. Ticket to Talk can support the redistribution of agency for the person with dementia, using tickets to position people with dementia as experts on conversational topics.

DISCUSSION

Ticket to Talk aims to encourage conversation between younger people and their older relatives living with dementia, yet the findings from the critique and use of Ticket to Talk show the applications of the technology have a broader effect on intergenerational relationships than simply encouraging the frequency of conversations.

Where Technology Ends

Life Story Works require a certain knowledge of someone's past and a large investment of time, and as such are rarely completed. This unavailability of LSWs exemplifies one of the younger people's biggest concerns: a lack of knowledge of someone with dementia's life history. This, in combination with the negative attitudes towards questions as conversational devices, makes instigating conversations daunting - echoing McNaney et al.'s co-design workshops [36]. Ticket to Talk helped overcome this obstacle by

providing younger people with inspirations, enabling them to capture snapshots of an older person's past experiences, which were then used to stimulate conversations. This resource of conversational topics gave them confidence in instigating conversations with people with dementia. However, without advice from the technology on how to approach the conversation, these tickets to could lead to an impersonal and indifferent conversation with someone with dementia.

Participants expressed the need for a guide to advise younger people on how to approach using media stored in Ticket to Talk during conversation. As McNaney et al. [36] discusses, a lack of conversation topics were a major hindrance in intergenerational communication, but even when these are present, younger people struggle to use them in conversations. The implication for technologies such as Ticket to Talk is that, in order to support conversations effectively, technologies should provide practical conversational guidance for younger people. Technology can only go so far in providing topics of interest, but this alone does not spark a conversation. Instead, it requires younger people to employ a sensitive approach in their use of media, with respect to the difficulties of living with dementia. This approach requires a level of conversational skill some younger people might not have but technologies like Ticket to Talk can give advice on the presentation of media, such as: tips on not framing the media as a question; changing media slowly to avoid confusion; and using devices with larger screens. With this advice, conversations could become inquisitive, yet still empathetic.

Past and Future Based Conversations

Blythe et al. [9]'s use of the "Tickets to Talk" metaphor created future facing talking points, focussing on events or technological interventions in a care home. The critique of our Ticket to Talk application expressed a desire for future facing tickets, allowing conversations to become an exchange between younger people and people with dementia. People with dementia may require more support to engage in a conversational exchange, but if Ticket to Talk can encourage this type of use then conversations can become more enjoyable and meaningful for both parties - deepening an understanding of social identity and personal experiences. One of the participants offered advice in moving towards this conversational configuration: *"you have to also allow them to be involved in your problems"*, understanding that, despite having dementia, people can still have advice to share. The inspirations in Ticket to Talk help configure these interactions, enabling families and younger care workers to move towards a more person-centred care based approach. Younger people can create tickets which further an enjoyable relational exchange, as seen in Blythe et al.'s future orientated tickets, rather than the sometimes-limiting retrospective tickets that encourage reminiscence.

However, when future facing tickets were available for some younger people, reminiscing over a shared experience

was the preferred format of conversation. Conversations were formed around predefined anchor points, events their older relative were likely able to recall. Encouraging reminiscence in Ticket to Talk received criticism for excluding the relative with dementia from sharing negative emotions the younger people experienced, or remembering negative emotions associated with their past memories. Furthermore, continued conversations on reminiscence may locate people with dementia in the past, perhaps inviting comparison between the two versions of the older person. Reminiscence has been seen as a positive thing in previous literature, with Wallace et al.'s 'Tales of I' [53] and design probes [54] showing the sense of connection and closeness reminiscence can create. This is mirrored in Ticket to Talk as families can reconnect over tickets of old memories. In Ticket to Talk this frequent shared reminiscence for the younger people and people with dementia resembled reminiscence therapy, but in a more casual setting.

Lazar et al. [29]'s description of technology's role in reminiscence therapy show its primary use as supporting therapists in configuring sessions. There are clear benefits to reminiscence therapy, such as reducing depressive moods, agitation, and caregiver strain [8,15,34,35,55,58]. However, the technologies Lazar et al. describe overlook technology's role in more casual forms of reminiscence, such as the form observed in Ticket to Talk. These sessions of reminiscence arise in everyday conversations for people with dementia, in an effort to create comfort not just for people with dementia, but also for their families and wider care ecologies. Reminiscence therapy generally occurs at a clinical level, but technology can be used to increase its access - making reminiscence a part of the mundane and daily interactions. While the benefits of reminiscence are reduced, there is still the potential to experience similar positive effects on mental wellbeing for people with dementia and those in their immediate care ecology.

Influencing Agency

Ticket to Talk was used to record memories and experiences of older relatives, or even themselves should they develop dementia. This use of Ticket to Talk shows a deliberate attempt to reposition someone with dementia to increase their agency in different social settings. Recording memories required younger relatives to configure social situations such that someone with dementia could share their stories and lead the conversation. In these moments, conversations were a relational exchange, where people with dementia had an opportunity to resume past social roles, in order to share experiences, stories, or give advice to a young person. This allowed young people to learn more about the identities, and experiences, of the people with dementia with whom they conversed.

This repositioning of agency is an indirect consequence in the literature outlined above, for example: where Wallace et al. [53] place residents in a more comfortable environment - easing the process of reminiscing and sharing their stories; or where Ryan et al. [48] reposition people with dementia

receiving care from their families, as people who now have a voice to express their current experiences. However, in Ticket to Talk, this becomes explicit when participants preserve their own interests and experiences in the application. They preserve their own familiar social power dynamics and methods of communication in preparation for later life. This preserved familiar social setting then acts as a conduit for expressions of self and personhood. This is useful for technologies like Ticket to Talk, as these technologies can be used to give people with dementia more agency within their social settings. For instance, during the family exit interviews the older relative with dementia was simply asked “What stories do you want to share with your younger relatives?”, from this the researcher and his daughter were invited to share in his past experiences, many of which his family had no knowledge of.

Ticket to Talk has a clear value in supporting intergenerational interactions between younger people and people with dementia, creating confidence and instigating enjoyable conversations for both parties. However, the technology alone cannot create meaningful and empathetic engagements; it requires the younger people to take a thoughtful and sensitive approach towards people with dementia. Killick & Craig [24] stipulate there is a change in communication with people with dementia, rather than a loss of ability to communicate. They argue the impetus to understand this change is placed on us, rather than the person with dementia to make up for the deficit. The use of a guide on the pragmatics of conversation - such as knowing when to listen, or share a different world view - can help level the communicative playing field and form a common language between young people and people with dementia. The guide can impart advice on how to use technology empathetically, echoing the approaches outlined by Wright & McCarthy [56] and Lindsay et al. [32] in getting to know someone and sharing an understanding of their life experience. With this, the use of Ticket to Talk can radically change the manner in which young people engage with people with dementia. Using technology to record a life history requires the younger person to give control of the conversation to someone with dementia, so that they can listen to and discuss the stories they want to capture. The technology can be used to create safe conversations and instil confidence in young people, or, it can help redistribute agency in people with dementia's favour - allowing a more person-centred care approach from their care ecologies. Noted by participants was the need for a guide to help young people approach conversations and the use of tickets in an empathetic manner. In technologies like Ticket to Talk, this guide should offer advice on how to use media inquisitively, yet be sensitive to the challenges of dementia. Furthermore, it should offer advice on how to configure conversations so that people with dementia have a space to share their stories, but also be listened to.

Limitations

It is difficult to generalise the implications from this evaluation of Ticket to Talk, as with most qualitative research [31], given differences in experiences of dementia and family dynamics. It is also difficult to recruit families given the domain and ethical restrictions [19], which were mitigated in this project through evaluating the application across three different settings. However, the identified themes were present in all settings. Ticket to Talk helped begin redistribute agency in families but also proved effective in positioning care home residents as leaders of conversations and discussions. The critique workshop identified reciprocity as a key criterion in maintaining conversations, whilst families reported a shift from functional to reciprocal conversations as one of the major changes in their interactions after using the application.

CONCLUSION

We present Ticket to Talk as a novel technology that encourages and supports conversations between young people and their older relatives living with dementia. Ticket to Talk achieves this through the collection and curation of digital media related to an older relatives' past experiences, providing talking points for young people. The project identifies the themes of ‘promoting and managing reminiscence’, ‘starting and maintaining conversation’, and ‘redistributing agency’ as its findings. We discuss: the benefits and challenges in promoting and managing conversations; the methods of using digital media to stimulate intergenerational interactions; and finally, the positive and negative ramifications of using technology to influence people with dementia's agency in social settings. Ticket to Talk can be used to position people with dementia as story tellers and advice givers, bridge conversational gaps, and reaffirm connectivity in families.

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